



Empathize • Organize • Mobilize

Survivor Corps Overview

April 2021

Survivor Corps

The Epicenter of Hope

Survivor Corps is the largest grassroots movement in America dedicated to actively ending the COVID pandemic. Our mission is to connect, support and educate those affected by COVID-19. We aim to mobilize as many as possible to support all ongoing scientific, medical and academic research.

Our work is influencing the development of new therapeutics for those with COVID and improved care for those suffering from Long COVID/PASC. As of April 2021, there are over 165,000 members of Survivor Corps.

Research

Survivor Corps has redefined what it means to be a citizen scientist. By working and collaborating with researchers and clinicians around the world, the organization and its members have participated in groundbreaking and critical research in the fight against COVID-19.

Studies Include:

- Indiana University School of Medicine/Survivor Corps Symptom Survey Publications
- Columbia University Dept of Medicine, Division of Digestive and Liver Disease
- Long term COVID studies (CDC Inspire, Stanford autonomic dysfunction, JHU symptoms and recovery, UI/Mayo Brain Health, etc.)
- University of Michigan Institute for Social Research
- Stanford Healthcare Innovative Lab
- Adaptive Biotechnology T-Detect

Original Research:

Survivor Corps/Indiana University School of Medicine

Overview

Indiana University School of Medicine and Survivor Corps designed and conducted studies with members in the Survivor Corps Facebook group. Recruitment was also done through newsletters and other social media platforms.

Results

- 2 White papers - posted on our website: A Long Hauler Symptom report, An assessment of preventative screening methods based on symptoms reported
- medRxiv preprints: Timing, Duration and Health Impacts of PASC, & Symptom Clusters, and Predictors for Becoming a Long-Hauler
- See: www.survivorcorps.com/reports

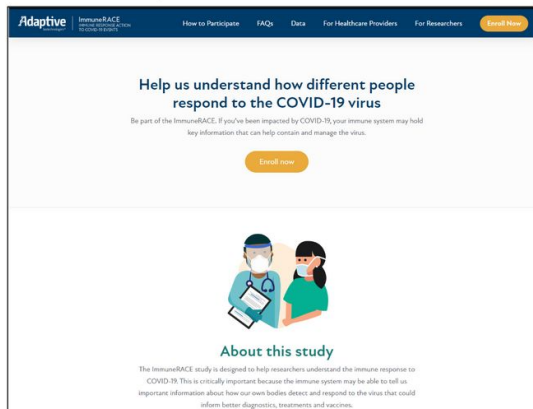
Insights from Survivor Corps Research

- Range of long-term sequelae, their timing, duration, and health impacts in terms of social impact, family impact, and ability to work
- Many PASC sequelae are intermittent, and this quality of sequelae makes it difficult for many survivors to return to work
- Symptoms arise in waves, which suggests neurological and cardiovascular manifestations, followed by microvascular consequences and then possible impact on endocrine function
- This finding can help to guide research on the biological processes underpinning PASC
- Process: SC polls have been essential for generating hypotheses about new sequelae, health impacts, barriers to care, the financial impacts of PASC, and health outcomes related to covid vaccines
- Future: Currently analyzing data to gain insights into effective care, symptom management and outstanding patient needs

Contributions To Science: Adaptive Biotechnologies T-Detect

From Bench to Bedside: Contributions to Clinical Research

Survivor Corps contributions to Research: ImmuneRACE



- Clinical study participation
 - Several key members of Survivor Corps participated, and drove patient participation in the prospective ImmuneRACE study
 - Contribution to the largest public database of immune response to the virus (ImmuneCODE)
- Ongoing patient education
 - Two webinars to educate patients on the basics of the immune system and T cells
- Informed development of the first clinical T-cell test to detect past COVID-19 infection (EUA authorized)
 - T cells last longer than antibodies, therefore a T-cell test is an important tool for people who want to know if they had COVID-19 and may help them to understand and address ongoing health issues

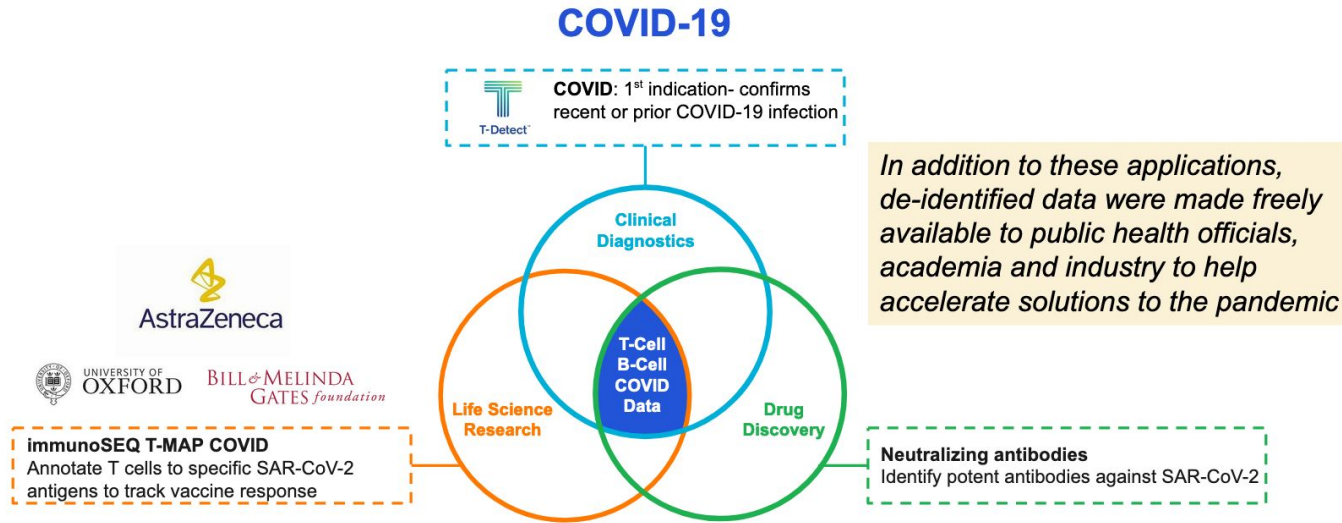
"Survivor Corps has been leader in encouraging patient participation in research, enabling direct contributions to scientific breakthroughs during this public health crisis. Because of these contributions, patients around the world are already benefiting from advances made in the diagnosis and treatment of COVID-19."

- Lance Baldo, Chief Medical Officer, Adaptive Biotechnologies

Source:
Adaptive
Biotechnologies

Contributions To Science: Adaptive Biotechnologies T-Detect

Immune response data informed important research and clinical applications



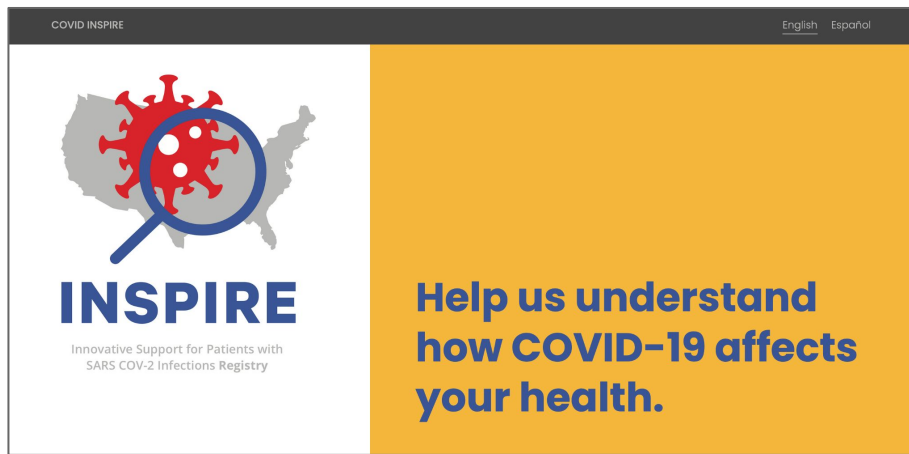
Source:
Adaptive
Biotechnologies

Contributions To Science:

Inspire Study

Overview

Example: CDC Inspire Study



Results

- Survivor Corps conducted question review for study
- Assessed user interface
- Promoted on social media (in English and Spanish)
- Drove recruitment

Future Studies

Long COVID focused studies submitted to the NIH for consideration

Overview

Survivor Corps is collaborating with researchers to support the development of new studies focused on understanding Long COVID.

Potential Studies

- Children with Long COVID
- Multi-state longitudinal studies on PASC
- Localized PASC studies combining surveys, bio-specimens, testing, and treatment success
- Focused biological (blood, saliva) collection studies to understand the underlying mechanisms of PASC
- Scanning studies to identify organ health in PASC patients
- Studies targeting treatment potential for specific symptoms (for example: headaches, GI issues, sleep disturbance and fatigue)

SurvivorCorps.com

The Survivor Corps website (www.SurvivorCorps.com) is a central hub for information for those affected by COVID-19, including patients, caretakers and physicians.

The United States Library of Congress selected the Survivor Corps website for inclusion in the nation's historic Coronavirus Web Archive.

Website Topic Areas:

- Research and Clinical Study Opportunities
- Therapeutics
- Educational Resources
- News and Media
- Post COVID Care Center Guidelines and Locations
- Physician Resources
- Digital Resources for Social Media
- FAQs

Overview

- Portal on the Survivor Corps website dedicated to assisting those who are newly diagnosed with COVID-19 on assessing their potential eligibility for monoclonal antibodies and accessing treatment
- Links to HHS & National Infusion Center resources
- Information on clinical trials for those who do not qualify under the current EUA
- Comprehensive FAQ section
- Medical Facility and Physician Resources
- Content is available in English and Spanish

The screenshot shows the Survivor Corps website's eligibility assessment for COVID-19 treatment. The header includes the Survivor Corps logo and navigation links. The main heading is 'Tested POSITIVE for COVID-19?'. Below this, a note states: 'Click the appropriate category to find out if you qualify for Monoclonal Antibody treatment - and where to get it, when given in the first 10 days of illness, treatments can prevent hospitalizations and/or severe complications caused by COVID-19.' The form is divided into four columns, each with a 'YES' checkbox and a list of conditions:

- Are you 65 or older?** (YES checkbox checked)
 - Cardiovascular Disease or
 - Hypertension or
 - COPD or
 - other chronic respiratory disease?
- Are you 55-64 years old AND have...** (YES checkbox checked)
 - Diabetes Mellitus or
 - been diagnosed with an immunosuppressive disease (weakened immune system) or
 - a current immunosuppressive therapy?
- Are you 18+ years old AND have...** (YES checkbox checked)
 - Body Mass Index (BMI) over 35 or
 - Chronic Kidney Disease or
 - Diabetes Mellitus or
 - been diagnosed with an immunosuppressive disease (weakened immune system) or
 - a current immunosuppressive therapy?
- Are you between 12-17 years AND weigh 88 lbs (40kg) min. AND have...** (YES checkbox checked)
 - Obesity (BMI a 95th percentile for age) (gender based on CDC growth charts), or
 - Sickle Cell Disease, or
 - Congenital/Acquired heart disease, or
 - Neurodevelopmental Disorders (Cerebral Palsy), or
 - medical-related technological dependence (e.g. Tracheostomy, Gastrostomy, positive pressure ventilation rig) related to COVID-19, or
 - Asthma or
 - Reactive airway disease or
 - any other chronic respiratory disease that requires daily medication?

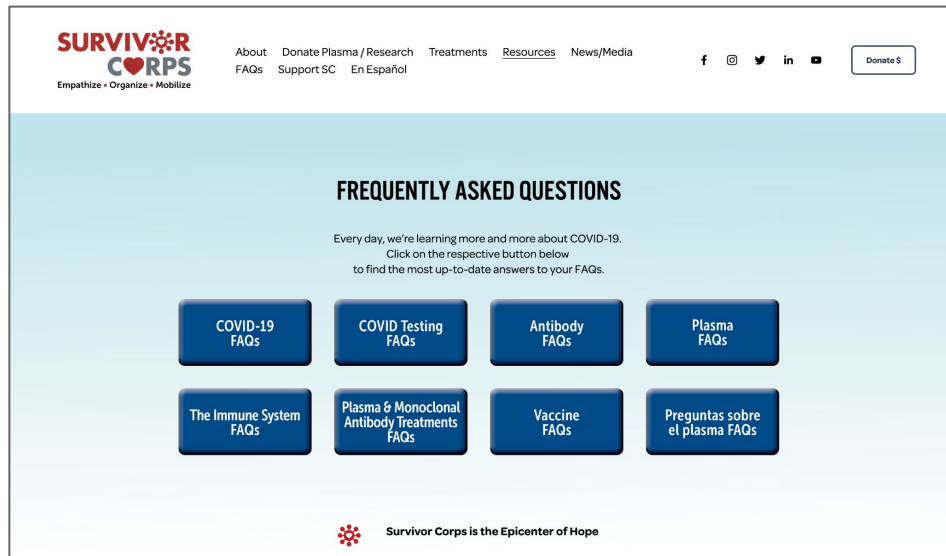
Below the assessment, a dark blue banner states: 'If you CANNOT answer "Yes" to any of the above and are NOT over 65 years of age, consider joining one of these Clinical Trials to receive treatment:'. It features four clinical trial options: 'Lilly Clinical Trial', 'REGENERON Clinical Trial', 'Lilly NIAID Blaze-2 Study', and 'NIH ACTIV-2 Clinical Trial'. At the bottom, a white banner says: 'DON'T WAIT! CONTACT A TREATMENT LOCATION TODAY'.

SurvivorCorps.Com

FAQ Section

Overview

The FAQ section acts as a guide for users to get their questions answered on multiple topics.

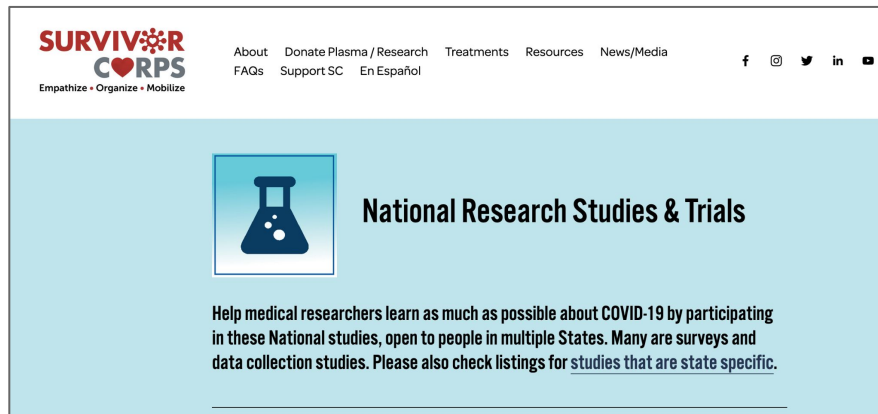


SurvivorCorps.Com

Research Opportunity Library

Overview

Survivor Corps promotes research studies relating to COVID-19. Topics include therapeutics, Long COVID, vaccines, patient narratives and equity in care.



SurvivorCorps.Com

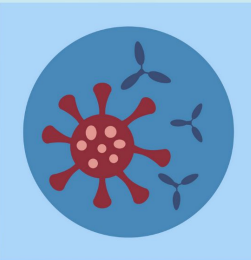
Physicians Resources Page

Overview


In an effort to fill a communication gap caused by the overwhelming demands on the healthcare industry during the pandemic, Survivor Corps has developed resources for physicians and healthcare facilities.

RESOURCES FOR PHYSICIANS AND HEALTHCARE PROFESSIONALS

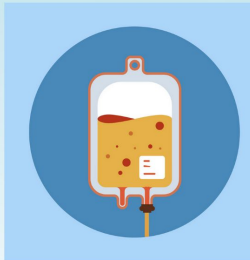
These resources and links have been developed for health care providers to assist them in accessing best practices and developing effective care strategies for newly diagnosed, acute and long term COVID patients:



Physician Resources: Monoclonal Antibodies



PCCC: Guidelines for Multidisciplinary Post COVID Care Centers



Plasma: Latest AABB Updates

Relevant Links: COVID-19

SurvivorCorps.Com

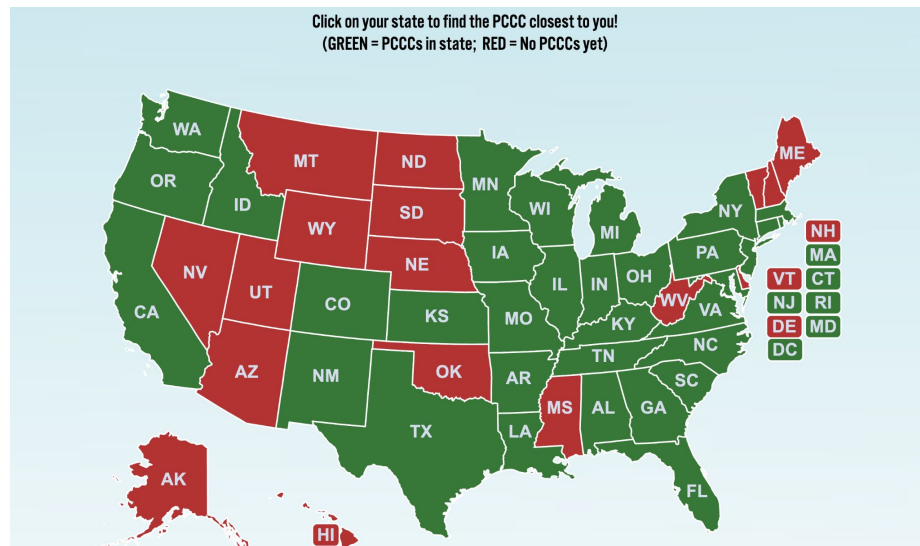
Post COVID Care Centers

Overview

The Survivor Corps website offers a comprehensive location map and listings of Post COVID Care Centers, Rehabilitation Facilities and Acute Care Centers around the country.

In addition, suggested guidelines are provided to those facilities seeking to set up healthcare programs for those with Long COVID.

www.survivorcorps.com/pccc



Topics Have Included:

- Long COVID
- Plasma
- Mental Health
- Monoclonal Antibody Treatments
- Symptom Specific Discussions
- Timely Update on COVID
- T-Cells and Immunity
- Vaccines

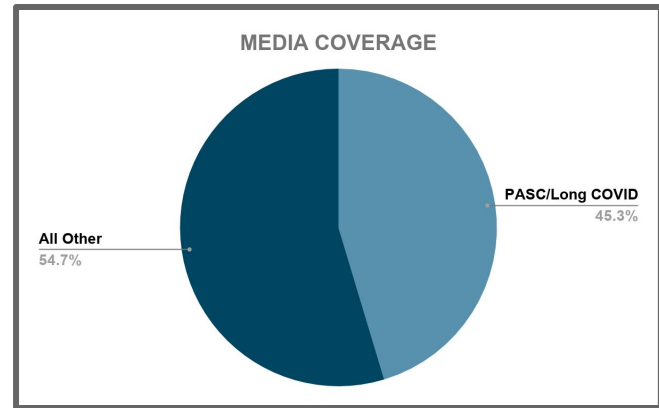
Expert Panelists Have Included:

- Dr. Anthony Fauci
- Dr. Andrew von Eschenbach
- Dr. Michael Joyner
- Dr. Kavita Patel
- Dr. Daniel Griffin
- Dr. Vin Gupta
- Dr. Lance Baldo
- Dr. Emma Guttman
- Dr. David Putrino

Survivor Corps Media Reach

In the 13 months since its founding, Survivor Corps has been featured in over 4,000 media pieces with a reach of over 13.6 Billion.

Coverage on PASC/Long COVID makes up over 45% of coverage. "All other" coverage includes vaccines, therapeutics, personal testimony and equity.



Survivor Corps The Epicenter of Hope

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